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Carer engagement in the hospital care of older people: An integrative review

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Review

**CARER ENGAGEMENT IN THE HOSPITAL CARE OF OLDER
PEOPLE: AN INTEGRATIVE LITERATURE REVIEW**

ABSTRACT

Background: Carer engagement can help to improve the delivery and continuity of care provided to older people in hospital. However definitions, guidance and structures for carer engagement in hospitals are lacking and there can be tensions and conflicts about the role of carers in hospitals.

Aim: The aim of this review was to explore the concept of carer engagement in the hospital care of older people and to build theory to inform future research and practice.

Method: Integrative literature review. Literature searches identified 2,745 peer-reviewed articles and studies published between January 1990 and November 2015 in the following databases: PubMed, Cochrane, Medline, EMBASE, and CINHALL. After applying inclusion/exclusion criteria the sample (103 articles) was subject to thematic analysis.

Results: Current evidence on carer engagement is dispersed across different research literatures on clinical conditions and contexts. Six distinct components of carer engagement were identified: patient caregiving, information sharing, shared decision making, carer support and education, carer feedback and patient care transitions.

Conclusion: Hospitals can adopt a more consistent and comprehensive approach to carer engagement for older people by developing and supporting the different components of carer engagement identified.

Implications for practice: The integrated model of carer engagement developed here could help staff and hospitals to develop strategies, staff training and resources that work with rather than against carers. The findings can inform future research on carer engagement interventions and associated outcomes for patients, carers and staff.

Key words: Carer engagement, carer involvement, family caregivers, older people, acute care

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IMPLICATIONS FOR PRACTICE

What does this research add to existing knowledge in gerontology?

- Carer engagement in the hospital care of older people is an important health care issue internationally yet theory and evidence to inform hospital practice is lacking.
- An integrative review of the research literature on carer engagement in the hospital care of older people identified six distinct components of the construct which inform an integrated model of carer engagement.

What are the implications of this new knowledge for nursing care with older people?

- Carer engagement concerns all inpatient areas caring for older people, it should not be limited to specialist services for older people.

How could the findings be used to influence policy or practice or research or education?

- These findings can inform carer engagement policy, research and practice which could help to ensure patients and carers are satisfied with their care, improve health outcomes and enable hospitals to meet the care needs of an ageing population.

BACKGROUND

The United Kingdom (UK) National Health Service (NHS), like many other health care systems internationally, is currently facing some considerable challenges to deliver and improve the hospital care provided to an aging population (Ferlie and Shortell, 2001; Lindhardt et al., 2006; Oliver et al., 2014;). Most people (65 per cent) admitted to NHS hospitals are older than 65 years (Cornwell et al., 2012). Older people are often living with multiple long term conditions, requiring a focus on both the presenting acute event and their ongoing bio-psycho-social needs during an admission (Cornwell et al., 2012). The challenges include providing continuity of care, with dignity and compassion (Levenson, 2007; Firth-Cozens and Cornwell, 2009; Abraham, 2011; Care Quality Commission, 2011; Francis, 2013). Breakdowns in continuity of care put patients at risk of functional decline (Hartgerink et al., 2015) and add avoidable costs to both health and social care (JRF, 2012b). This paper focuses on carer engagement as a possible way to address some of the challenges of delivering hospital care to older people.

The research literature suggests that carers can provide a range of support to older patients during their hospital care (Nolan et al., 2004; Patterson et al., 2011), which may help to overcome some of the challenges of care delivery. “Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management” (NICE, 2004, p. 155). Carer engagement can support the continuation of a person’s activities of daily living (Laitinen, 1993) and provide personalised support (Lindhardt et al., 2006). Although the role of carers is now recognised in the NHS Constitution (2013) and The Care Act (2014) carer engagement is poorly defined and there is very little relevant guidance for hospitals (NICE

Clinical Guidance 161, 2013; NICE Quality Standard 13, 2011; NICE Quality Standard 15, 2013;). Carer engagement is often seen as an extension of patient involvement in health care (Coulter, 2011; Barello et al., 2012; Tobiano et al., 2015) or as being covered by Patient and Public Involvement (PPI); which refers to activities to enable the direct and active participation of patients in decisions about healthcare delivery, service development or research (Fotaki, 2011; Barnes and Cotterell, 2011). However patient involvement and PPI are not only much broader concepts, supported by more formal structures (such as Patient Advice and Liaison services), they are more likely to involve non-clinical staff (e.g. managers or researchers), wider patient or community groups who may or may not be receiving hospital care. Furthermore, patient involvement in research or service development and delivery doesn't relate to a specific health event but to wider processes or experiences of patients and the public.

The definition of carer engagement used in this review is informed by existing research (in particular Barnes & Cotterell, 2011; Cornwell et al., 2012; and Carers Trust, 2014) and our own research with carers, patients and staff in NHS hospitals. Here we draw on these sources to suggest that "Carer engagement means the direct and active involvement of carers in older people's hospital care and attention to the caregiving relationships between carers, patients and clinical staff". There are some overlaps with family collaboration, which focuses on relationships between relatives and nurses, where relatives are seen as competent collaborative partners in care in decision making rather than passive recipients of information (Lindhardt et al., 2008a; 2008b; 2008c). However carer engagement is not limited to relatives and it may not be feasible or acceptable for carers to take on a collaborative role in patient care, particularly if carers have a non-familial relationship with the patient.

The role of carers in hospitals is predominantly controlled by professional priorities (Allen, 2000; Hancock et al., 2003; Porter et al., 2011) and practices (Nolan et al., 2004; Patterson et al., 2011; JRF, 2012a) rather than evidence of what works. There can be tensions associated with carer roles, such as staff/carers conflicts over care activities (Laitinen and Isola, 1996; Walker and Dewar, 2001; Nolan et al., 2004; Lindhardt, et al. 2008b; Jurgens et al., 2012). Very little is known about carer preferences, or how carer health or stress (Whittamore et al., 2014; Carers Trust, 2014; Oliver et al., 2014), cultural differences, age or gender might affect carer engagement (Li et al., 2004; Sandberg and Eriksson, 2009; Baider and Surbone, 2014). Existing models of family-centred care and relationship-centred care have shown to be helpful frameworks for practice, leading to better patient outcomes and carer satisfaction (Nolan et al., 2004; Hudson and Payne, 2009; Patterson et al., 2011). For example the notion of a Triangle of Care, developed in mental health, has been applied in dementia care to emphasise a more ongoing and interactive relationship between patient, carer and professionals (Carers Trust, 2014).

Little is known about carer engagement and research is needed to examine different aspects and perspectives of the issues to inform hospital practice. Carers can provide a range of support to older patients which could help to meet the challenges of providing continuity of care in hospitals, with dignity and compassion. However, there is a lack of clear definitions, evidence and guidance about carer engagement in hospitals. Greater understanding of the concept of carer engagement is a possibly effective way to identify and develop components of carer engagement in hospital care. Therefore, the purpose of this integrative review was to search for relevant literature and to develop understanding of the concept of carer engagement to inform future research and practice.

AIM

The aim of this review was to explore the concept of carer engagement in the hospital care of older people and to build theory to inform future research and practice. Specifically, the paper seeks to address the following research question: What are the components of carer engagement in hospital care for older people?

METHOD

Approach

An integrative review was chosen as it is the broadest type of research review method, allowing for exploration of concepts, theory building and the simultaneous inclusion of experimental and non-experimental research in order to more fully understand carer engagement (Cooper, 1984; Broome, 1993; Whittemore and Knafl, 2005). For rigour and validity it is important to be clear about the approach taken in this integrative review (Gough et al., 2012). One researcher (EM) undertook the literature searches as part of a much larger study on older people’s hospital care led by CN. Our experiences of research in NHS hospitals tells us that carer engagement exists but it is poorly defined and developed in health care practice. It is our view that some or all of the components of carer engagement are already present in the research literature (e.g. in accounts of carer interventions and observational studies) but have yet to be identified and defined in a way that is useful for research and practice. Review and interpretation of the data followed the logics and strategies of a structured literature review capable of identifying different components and distinguishing carer engagement from other information in the review process. The aim was

to find sufficient cases to explore patterns and so not necessarily attempting to be exhaustive in the searches (Gough et al., 2012). Implications for the searches were to achieve a degree of homogeneity of data around the concept of carer engagement using iteration in the review method, for example development of inclusion criteria over time and refinement of themes.

Cooper (1998) has delineated the process of conducting a research review as encompassing a problem formulation stage (explained in the background), a literature search stage, a data evaluation stage, a data analysis stage, and a presentation stage. This framework is used below to explain the review method, illustrated by figure 1 (Figure 1).

[FIGURE 1 TO GO NEAR HERE]

Literature search

Multiple literature searches were undertaken based on keywords derived from our definition of carer engagement set out in the introduction (Gough, 2012). Having a specific focus on carer engagement in the hospital care of older people facilitated a structured search strategy based on the target group (carers of older people), the concept, and the hospital context. The validity of key terms was tested using preliminary searches and was considered suitably broad to capture articles on carer engagement. In addition to keyword searches the PubMed database was used to search for the most recent literature using MeSH (Medical Subject Headings) (Table 1). Functional limits applied in the searches were: English language and years 1990 to 2015. A theoretical approach to sampling was used to identify a sufficient and appropriate range of studies based on the existing body of literature (Gough et al., 2012) (akin to purposive sampling in primary research). The database searches identified 2,745 articles. In the first stage of screening EM read all returned article titles and abstracts, and

where necessary the full article to gain further detail about article content. A broad age category (60 years and over) was used to include articles about the young-old and the old-old, and to include patients on elderly care wards as well as general adult inpatient settings (Cornwell et al., 2012). EM and CN discussed the relevance of specific articles where it was not clear whether articles should be included or not. This initial reading was followed by further familiarisation with the returned articles by both authors, sharing information and reflecting together on article content to develop a framework of inclusion/exclusion criteria. As screening progressed the criteria were further refined in an iterative process of reading, modifying the criteria and screening to reduce the number of articles to the most relevant (Table 2). The validity of the draft inclusion/exclusion framework was tested through discussions with two project supervisors and with members of the study advisory group (including NHS staff and carers of older people) for resonance with lay and professional understandings of carer engagement. A further 30 articles were collected through manual searches of reference lists of the included articles. After screening the final sample was 103 articles.

[TABLE 1 TO GO NEAR HERE]

[TABLE 2 TO GO NEAR HERE]

Data evaluation

The final sample included empirical and theoretical articles. Empirical reports included a wide variety of methods: case study, cross-sectional, grounded theory, phenomenology, and instrument development designs. Review studies were included as well as primary sources where these provided a distinct contribution or theoretical perspective about carer

engagement. Due to the diversity of primary sources articles were considered according to two criteria: data relevance and methodological/theoretical rigour. Judgements about data relevance were based on the focus of articles on carer engagement for older people in the hospital context (High/Moderate/Low) (illustrated in column two of table 2). Judgements about the quality of the evidence were informed by Grading of Recommendations Assessment, Development and Evaluation (GRADE) (Balslem et al., 2011). The GRADE approach specifies four levels of quality (High I- Very low IV) based on methodology: randomized trials or double-upgraded observational studies (I: High), downgraded randomized trials or upgraded observational studies (II: Moderate), double-downgraded randomized trials or observational studies (III: Low), triple-downgraded randomized trials or downgraded observational studies or case series/case reports (IV: Very low). As the focus was to explore carer engagement rather than to review evidence of effectiveness, no article was excluded based on methodological criteria alone. However in general, articles of high rigour and relevance were given more attention in the analysis and contributed more to the results.

Data analysis

The focus of the analysis was on identification and integration of information about carer engagement, rather than meta-analysis of the findings of studies (Denzin and Lincoln, 2000). Data were extracted from primary sources using a structured table in Microsoft Word (Table 3). CN and EM developed headings of the data extraction tables suitable to capture information about the context (patient/carers group, country, research methods and clinical context) and content relating to carer engagement (definitions of carer engagement, aspects of the process of carer engagement, antecedents, consequences, and impact/how the findings facilitate carer engagement). EM extracted the data from each article and CN checked the

extraction process by reviewing a sample of extracted articles, as detailed in Noyes et al. (2011). A code framework was developed from the data to define patterns in the data and to distinguish between various components of carer engagement. Codes were then grouped together into potential themes which were reviewed to ensure that the overall code framework reflected the research question and the content of the data set (Braun and Clarke, 2006). Data tables were used to display the coded data from each article by category and were iteratively compared. The reviewers discussed their decisions and interpretations with one another throughout the process.

[TABLE 3 NEAR HERE]

Presentation

A synthesis in the form of a model was developed to comprehensively portray carer engagement in the hospital care of older people. Descriptions for each component of carer engagement were developed and relevant data from primary sources was summarized to create an overview of the included literature.

RESULTS

Overview of the findings

Current evidence on carer engagement is dispersed across different research literatures on clinical groups, clinical contexts and countries, summarized in table 4 (Table 4). The underpinning research uses a range of qualitative (case study, interview, grounded theory, ethnography), quantitative (cross-sectional, quasi-experimental), review (meta-analysis,

literature review) and action research methods. The overall quality of the body of evidence is moderate according to GRADE criteria (downgraded randomized trials or upgraded observational studies). The relevance of all of the included articles were judged as being High or Moderate, adding validity to the literature search process and our use of the inclusion/exclusion framework. Over a third of the articles related to older patients generally, with the remainder relating to specific groups/clinical conditions of which dementia, frailty and palliative/end-of-life were the most common. Topics addressed in the articles related to six major themes (Table 4) which concern different components of carer engagement: patient caregiving, shared decision making, information sharing, support and education, carer feedback, and patient care transitions. These components of carer engagement are explained in turn below.

[TABLE 4 TO GO NEAR HERE]

(i) Patient caregiving

Patient caregiving relates to such terms and practices as – “looking after the person”, “personal care”, “preventing loneliness”, “helping patients to cope and feel in control”, “maintaining function”, “helping with rehabilitation”, “dementia support”, and “delirium prevention”, all of which describe situations in which patients are supported by carers to various degrees, in their treatment or care. This theme includes research about carer expectations and preferences about their role in patient caregiving, staff working with carers in the delivery of patient care, and the quality of caregiving. Studies have examined carer engagement in the physical and emotional care of the patient, including supporting nutrition (Marshall et al., 2013), personal care (Walter-Ginzburg et al., 2001), mobility (Nahm et al., 2010) and daily-living while in hospital (Clissett et al., 2013). While the role of informal

carer appears to be understood internationally, cultural norms concerning caregiving, systems of health care funding, and the availability of support have an impact on carer engagement (Yang and Kirschling, 1992; Cho and Kim, 2006; Baider and Surbone, 2014). For all patients, hospitalization is a time of disruption from normal routine and carers may respond to disruption proactively by trying to make sense of the situation and attempting to gain control for themselves or the patient (Lane et al., 2003; Lindhardt et al 2008c). As a result carers can value the support of hospital staff and services or be highly critical of the care provided (Clissett et al., 2013). Carers' behaviours to prevent the patient from feeling alone (Berthelsen et al., 2014) include providing loving and respectful support, practical and cognitive support. Carers may, unprompted by staff, adopt practices to manage nutrition (Marshall et al., 2013), provide cognitive stimulation (Yunhas et al., 2006; Health Quality Ontario, 2008; Woods et al., 2012), support physical recovery (Small et al., 2009; de Vos et al., 2012; Boltz et al., 2014) or prevent falls (Avila et al., 2015). Studies of caregiving have focused on improving partnership working between carers and staff generally in elder care environments (Laitinen, 1996; Bridges and Fuller, 2014) and specifically in relation to communication support (Carers Trust, 2014). An intervention study of Creating Avenues for Relative Empowerment (CARE) (Li et al., 2003) showed positive effects on carer participation in care and patient outcomes (confusion, incontinence and depression). Another intervention study where family carers were encouraged to room-in with patients overnight helped to decrease confusion, complications, and length of stay (Wells and Baggs, 1999). However, an 'activation programme' in Finland to involve carers during the hospital stay did not show any measurable effects (Laitinen-Junkkari, et al. 2001). Research on the quality of informal caregiving has identified the risk profile for potentially harmful caregiver behaviour (Beach et al., 2005) and generated guidance about assessment (COPE-Index) of caregiver support (McKee et al., 2003).

(ii) Shared decision making

Shared decision making relates to such terms and practices as – “being involved in treatment choices”, “care planning” and “best care decisions”, which describe situations in which patients are supported by carers to understand or make decisions about their treatment or care. This theme includes research about negotiation of decision making (Allen, 2000), carer participation in professional meetings (Griffith et al., 2004), advanced care planning (Ng et al., 2013), and staff/carer decision making relationships (Karlsson et al., 2015). Carer engagement in shared decision making becomes a necessity in the case of patients that are not able to make decisions about their care, for example due to dementia (Milte et al., 2013; Karlsson et al. 2015). Carer engagement in shared decision making can challenge established cultures of professional control over caring processes (Allen, 2000; Jacelon, 2006) and expectations about the roles of staff and carers (Walker and Dewar, 2001). It can require extra time and modification of technical language (Milte, et al. 2013). Hence, research in this area has sought to create tools and guidance to support staff to involve carers in decision making about patient care (Walker and Dewar, 2001; Firth-Cozens and Cornwell, 2009; JRF 2012b; Brief Encounters, 2014) and to open up professional decision making spaces to carers, such as multidisciplinary team meetings or best interest meetings (Griffith et al., 2004). Carer reported markers of satisfactory involvement in decision making include: feeling that information is shared; feeling included in decisions; feeling that there is someone you can contact when you need to; and feeling that the service is responsive to your needs (Walker and Dewar, 2001).

(iii) Information sharing

Information sharing relates to such terms and practices as – “sharing information about the patient’s condition or history”, “helping staff to see the patient as a person”, “supporting

communication between the patient and staff” and “carers feeling informed and involved”, which describe situations in which patients are supported by carers communicating information with staff. This theme includes research about carer knowledge of patient’s health and journey through care, carer involvement in patient assessment and carer/staff communication. Information sharing between carers and staff is effective if carers are actively involved in formal patient assessments, such as Comprehensive Geriatric Assessment (Ellis et al., 2011) and readiness for discharge to home (Pennbrant, 2013). Structured patient information tools can help staff to share information between staff and to see the person they are working with, by understanding their interests, preferences, likes and dislikes (Bradway and Hirschman, 2008; Goodrich and Cornwell, 2008; Alzheimer’s Society, 2014). Life story work involving people with dementia, carers and staff has been shown to enhance care through sharing information about a patient’s personal history, relationships and interests (McKeown et al., 2010; Thompson, 2011). There is an association between staff communication with carers and the patient’s perceptions of care quality (Cornwell et al., 2012; Robben et al., 2012). The negative impact of poor communication of information by staff has also been observed, for example qualitative research with a small sample of family carers of older patients undergoing haemodialysis in Norway revealed carer feelings of powerlessness because of a lack of dialogue with staff (Aasen et al., 2011). Simple communication strategies focused on sharing information can improve carer and staff experiences with potential safety benefits (e.g. reduced falls risk) for patients with dementia (Bradway and Hirschman, 2008; Luxford et al. 2015). However, interview research with frail older people and their carers (Robben et al., 2012) shows individuals vary in their information needs but participants generally preferred verbal information from staff accompanied by brief, clearly written information leaflets. Survey research of families with a hospitalized older relative who had delirium (Toye et al., 2014) suggests the need for

informational support outside of delirium-specific units and targeted information for male relatives. Other research reveals poor uptake of family communication tools and family conferences by providers, use of electronic checklists, and provision of staff education despite staff buy-in (Kodali et al., 2015).

(iv) Carer support & education

Carer support and education relates to terms and practices including “becoming a carer”, “coping with caring and stress”, “learning about the condition”, and “knowing how to help the patient” all of which describe situations in which carers are enabled through support and education. This theme includes research about staff recognition and valuing of the carer role (Morris and Thomas, 2001; Nolan, 2004; Patterson et al., 2011), carer support needs (Li 2005; Toye et al., 2014), interventions to reduce carer stress (Li et al., 2004; Lin and Lu, 2005; Given and Sherwood 2006), carer education about the patient’s condition (Li et al., 2004), and carer training for caregiving skills (Hendrix et al., 2011: 2013a). A pilot study using qualitative research on family caregivers of hospitalized elders shows carers may need support from staff (e.g. information about the patient's condition, care received, and their role in future care and finances) (Li, 2005). A feature of research within this theme is that carers of older people tend to be older themselves, with their own health problems and support needs. For example, interview research with 41 carers of frail older people found 85% had health problems that affected their caregiving, suggesting that differential planning based on each of the caregivers' needs can maximize the care they provide (Abraham and Berry, 1992). The Self-Care TALK resource guide, developed in the US, supports and extends older caregivers' self-care skills and abilities (Leenerts et al., 2007). Qualitative studies of carers of people with dementia (Douglas-Dunbar and Gardiner, 2007; Rosenbloom et al., 2010; Rosenbloom and Fick, 2014) and motor neurone disease (Hornsey, 1994) also conclude the

need for hospital staff to develop a therapeutic relationship with the carer, for the benefit of both patient and carer. Questionnaire-based interviews with 98 patients with hip fracture and their caregivers in Taiwan (Lin and Lu, 2005) found that caregivers who are unable to access support experienced higher burden (Lockery et al., 1994; Slatyer et al., 2013). Older carers caring for older patients require accessible support. An evaluation of teleconferencing support (McHugh et al., 2012) provided to carers (n=8) of people with dementia in the United States (US) found important issues were group processes, external facilitation and barriers to communication (the need for user-friendly technologies). While a pilot intervention study providing an individualized training program to carers of hospitalized older veterans in the US (Hendrix et al., 2011), found carer participation in training is associated with increased self-efficacy and caregiving preparedness.

(v) Carer feedback

Carer feedback relates to terms and practices including “explaining concerns to staff”, “telling staff how you are coping”, “views about care being provided”, and “cause for complaint or dissatisfaction”, all of which describe situations in which carers give feedback to staff about patient care or their experience of caring. Carer feedback may extend beyond carer engagement as it is defined here (see background) to include research about carer views and perspectives about caring beyond hospitals (Laitinen, 1993; Yeh and Bull, 2012), views about carer engagement in health care, satisfaction with coherence or quality of patient care (Mackenzie et al., 2007; Andrén and Elmståhl, 2008), and experiences of transitions between care environments (Digby and Bloomer, 2014). Accordingly many different methods of carer feedback exist and range to include carer engagement in clinical assessment of carer needs (Yeh and Bull, 2011), carer surveys (Andrén and Elmståhl, 2008; Laitinen, 1993), participation in research or evaluation studies (Rose et al., 2000; Mackenzie et al., 2007;

Matson, 1994), development of tools or resources in palliative care (Hudson and Payne 2009; Thomas and Moore, 2014) and contributing to professional education for dementia (Ellis, 2008). This theme focuses on carer engagement in feedback at the patient/ward level, but these activities may be linked to, or part of, carer engagement at the hospital level not included here.

(vi) Patient care transitions

Patient care transitions relates to terms and practices including “hospital admission” “discharge planning”, “moving wards” and “support for patients near end-of-life”, all of which describe situations in which carers support patients in their journey of care. This theme includes research about carer engagement in patient admission to hospital (Bowman et al., 1998), hospital discharge (to home or other care settings) (Bauer et al., 2009), and transitions from general medical or surgical care to specialist palliative or end-of-life care. Carer engagement in discharge planning has received considerable research attention and has shown the importance of family inclusion and education, communication between health care workers and family, interdisciplinary communication and ongoing support after discharge (Bowman et al., 1998; Shyu et al., 2000; Holzhausen, 2001; Walker et al., 2007; Popejoy, 2011; Giosa et al., 2014; Bragstad et al., 2014a; 2014b; 2008; Lundh and Williams, 1997). Intervention studies on discharge planning have combined teaching, assessment and home follow-ups (Naylor et al., 1994; Naylor et al., 1999; Lenz and Perkins, 2000; Mant et al., 2000; Bull et al. 2000) to engage carers and improve patient outcomes. In contrast a review of evidence on hospital discharge planning for frail older people (Bauer et al., 2009) shows a direct correlation between inadequate practices and adverse outcomes and an increased risk of readmission. Furthermore, interviews with carers (n=12) of patients over 75 years (Knight et al., 2013) show inadequate explanations about medicines at discharge can lead to omission

of medicines or incorrect dosage. Challenges for carers can also include preparing the home, organising care at home, coping with emotional concerns (Neiterman et al., 2015) and delays in outpatient review (Mudge et al., 2013). Patient transitions may also refer to carer engagement in supporting patients through transitions in care delivery across settings (Coleman et al., 2004) or provision of specialist/end-of-life care (Hanratty et al., 2014). Intervention studies (Coleman et al., 2004; Ellins et al., 2012; Hendrix et al., 2013b) and action research (Cotter et al., 1998) to improve patient transitions in care show that staff and carer communication and support through intra hospital or cross-site patient transfers are important for patient and carer outcomes. For example, the Care Transitions Intervention developed in the US (Coleman et al., 2004) includes tools to promote cross-site communication, patient and carer encouragement to take a more active role in their care and assert their preferences, and continuity across settings and guidance from a transition coach. Also developed in the US, a nurse practitioner-led interprofessional care model, called Transitional Care (TLC) Partners, supports the transition from hospital to home of older veterans and reduces rehospitalization (Hendrix et al., 2013b). Research within an integrated health and social care system in the UK (Baillie et al., 2014) shows transitions from acute hospital wards can be improved by removal of organisational barriers but family and carer involvement in care transitions was a major issue, alongside service integration and staff education.

DISCUSSION

This review shows that a range of types of carer engagement have been used internationally in hospital care but this tends to be limited to specific clinical or service problems (such as

hospital discharge). Identifying six different components of carer engagement helps to further define care engagement as a multifaceted element of hospital care. Although carer engagement manifested in quite different practices and actions in hospitals, there was a common theme to the underlying rationale – supporting the physical and emotional wellbeing of patients.

The findings echo reports in the literature that carer engagement can improve continuity of care by providing a consistent relationship for patients through the multiple and complex transitions in care older people are likely to experience (Ellins et al., 2012). Our findings suggest that an integrative model of care exists (Figure 2) and establishes carer engagement as a distinct element of hospital practice, with its own theory and evidence base, rather than an extension of patient involvement. Drawing on the idea of a triangle of care (Carers Trust, 2014) figure 2 illustrates the interrelationships between carer engagement and interactions between patient, carers and staff. This perspective acknowledges the ongoing and interactive contribution of the carer alongside the patient in their journey of care, rather than specifying a set role for carers in hospital settings. Unlike some previous interpretations of family-centred and relationship-centred care (Nolan et al., 2004; Hudson and Payne, 2009; Patterson et al., 2011), this perspective is sufficiently broad to inform carer engagement throughout all inpatient areas caring for older people, rather than being limited to specialist services for older people. It could encourage hospital staff to look beyond seeing families as the only providers of informal care: in most models there is limited understanding of the network of social relationships within which older people live their lives. This perspective addresses the need for a model that moves beyond family relatives or one named carer to multiple carers and dynamic engagement over time and place.

[FIGURE 2 TO GO NEAR HERE]

Strengths and limitations

The perspective taken in this integrative review influences the findings about what is known and not known from within those perspectives. The review focused on components of carer engagement rather than other perspectives, such as health care processes or effectiveness for example. The review focused on the hospital inpatient context and did not include evidence from research about carer engagement in outpatient contexts, long term care facilities or community settings, which would require further research. The searches were in the English language, so that evidence reported in other languages was not included. All articles were identified through peer reviewed journals or research reports, some grey literature (e.g. organisational reports and web-based information) was picked up through reference checking but there was not sufficient time search for grey literature searches or to contact authors about their articles. The main consequences of these limitations are that the study findings are limited to interventions reported in the academic literature which could exclude unpublished initiatives or ongoing improvements in hospital practice.

Implications for practice and further research

Developing carer engagement is not only about freeing up staff time in busy hospital environments (Patterson et al., 2011), it also concerns developing cultures of care that value and enable carer engagement (Lane et al., 2003). Indeed, carer engagement may offer a means to defend professional values – such as compassion and dignity – in pressurised hospital environments. There are significant implications for staff training and education, including developing carer engagement as a distinct element of healthcare course curricula and student assessment. Carer engagement could also be developed as a theme within staff

reflective practice and continuing professional development. Future research could test the integrated model with carers of different age, gender and ethnicity in the UK and internationally to see if it makes sense to them and to observe the effects of carer engagement. Such research should include development and testing of outcome measures in order to generate reliable evidence of the effects of carer engagement on patient outcomes, patient and carer experiences of care, and staff awareness and skills to meet older patients' needs.

CONCLUSION

This review supplements and extends knowledge of carer engagement by providing an overview of the existing evidence and presenting an integrated model to inform more consistent and comprehensive approaches to carer engagement in hospital care. Six components of carer engagement in hospital contexts are identified: patient caregiving, shared decision making, information sharing, carer support and education, carer feedback, and patient care transitions. Creation of a culture of carer engagement is an opportunity that hospital staff can use to improve continuity within existing structures and systems of care.

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For Peer Review

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CONFLICTS OF INTEREST

None declared.

CONTRIBUTIONS TO THE MANUSCRIPT

Study design (CN, EM), data collection and analysis (EM, CN), and manuscript preparation (EM, CN).

Figure 1: Flow chart of integrative review method

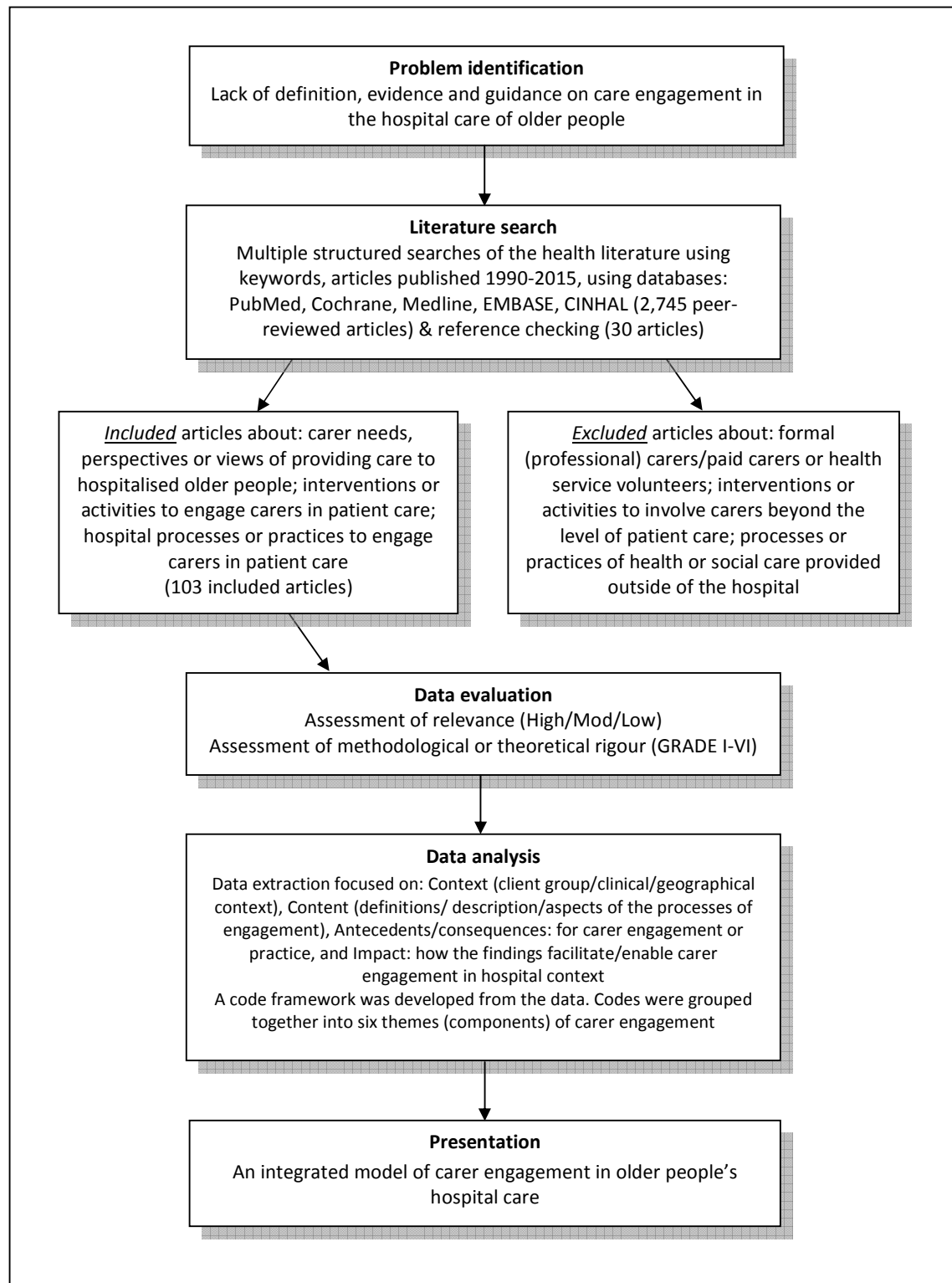


Table 1: Example search showing key words

| | |
|---|---|
| Database: | |
| PubMed | |
| Search query: | |
| (((carer[Title] OR caregiver[Title] OR family[Title] OR relative[Title]) AND (engagement[Title/Abstract] OR involvement[Title/Abstract] OR collaboration[Title/Abstract] OR participation[Title/Abstract] OR partnership[Title/Abstract] OR decision-making[Title/Abstract] OR information[Title/Abstract] OR communication[Title/Abstract] OR education[Title/Abstract] OR training[Title/Abstract])) AND ((older[All Fields] AND ("patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields])) OR (older[All Fields] AND ("persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields])) OR ("aged"[MeSH Terms] OR "aged"[All Fields] OR "elderly"[All Fields]) OR geriatric[All Fields])) AND (("hospitals"[MeSH Terms] OR "hospitals"[All Fields] OR "hospital"[All Fields]) OR ("Acute Care"[Journal] OR ("acute"[All Fields] AND "care"[All Fields]) OR "acute care"[All Fields])) | |
| MeSH Terms: | |
| patient | "patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields] |
| person | "persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields] |
| elderly | "aged"[MeSH Terms] OR "aged"[All Fields] OR "elderly"[All Fields] |
| hospital | "hospitals"[MeSH Terms] OR "hospitals"[All Fields] OR "hospital"[All Fields] |
| acute care | "Acute Care"[Journal] OR ("acute"[All Fields] AND "care"[All Fields]) OR "acute care"[All Fields] |
| Filters: | |
| AND ("1990"[Date - Publication]: "2015"[Date - Publication])) | |
| AND English[Language] | |
| Result: | |
| 1466 | |

Table 2: Inclusion/exclusion criteria

- i. **Included:** articles about carer needs, perspectives or views of providing care to hospitalised older people, defined as “Informal caregivers, family members, friends, relatives, or neighbours who have experience of caring for an older person in hospital”. Carers may be caring for patients with multiple morbidities, cancer, stroke, elective or emergency medical or surgical treatment, renal, respiratory or palliative care, and/or dementia.
- Excluded:** articles about formal (professional) carers/paid carers or health service volunteers.
- ii. **Included:** articles about interventions or activities to engage carers in patient care, including: participation, engagement or involvement in the delivery of hospital care to patients, carer participation in education, support or training provided within hospital settings, participation in research or interventions, engagement through carer feedback, collection of comments, surveys/ observations or feedback, consultation (e.g. focus groups, interviews, arts-based methods), health interventions or self-management programmes within the hospital setting.
- Excluded:** articles about interventions or activities to involve carers beyond the level of patient care, including hospital service development or quality improvement work, Patient and Public Involvement (PPI) in hospital design or management, national level service user groups/ networks, carer engagement in healthcare staff education or formal assessment outside of the hospital context, carer involvement in service-level quality monitoring and health service investigations.
- iii. **Included:** articles about hospital processes or practices to engage carers in patient care, including: patient or carer assessment, care planning or delivery of care, collection of patient information, delivery of basic or essential care (safety, nutrition, hygiene, dignity), communication, shared decision making, recognising and respond to changes in the patient, support for medicine management or self-care, best care or end-of-life care decisions, care planning and management of transitions in care, including discharge planning, helping to maintain independence or adjust to a level of need.
- Excluded:** articles about processes or practices of health or social care provided outside of the hospital (e.g. primary care, community or long term residential care).

Table 3: Data extraction table (extract)

| Reference (date) | Relevance/Grade of evidence: REL (High/Mod/Low) GRADE (High I- low IV) | Context: client group/ clinical/ geographical context | Content: definitions/ description/ aspects of the processes of engagement | Antecedents/consequences: for carer engagement or practice | Impact: How the findings facilitate carer engagement in hospitals |
|----------------------------|--|---|---|---|---|
| Alzheimer's Society (2014) | 'This is me' tool for carers. A downloadable leaflet, originally developed for people with dementia who were going into hospital, has now been updated and is relevant for people with dementia who are receiving professional care in any setting. (REL: High) (GRADE: IV) | A tool for people with dementia and their carers to complete that lets health and social care professionals know about their needs, interests, preferences, likes and dislikes. Relevant to carer engagement in a range of clinical contexts including hospitals. (UK) | Provides a central place for carers and patients to record patient personal information and preferences. It supports health and social care staff in the gathering of personal/ life history information from individuals with dementia, and in tailoring care more specifically to patient/carers needs. | 'This is me' is about the person at the time the document is completed and needs to be revised and updated as necessary through patient care. carer literacy. Possible issues of literacy, language, ownership and confidentiality of document. | Provides an accessible way for carers and professionals to share information about patients and their care. Facilitates communication and shared decision making. |
| Bridges and Fuller (2014) | Creating Learning Environments for Compassionate Care (CLECC) uses workplace learning to promote change at unit/ward/team level by enabling the development of leadership and team relational practices which are also designed to enhance the capacity of individual team members to relate to older people. (REL: Mod) (GRADE III) | Aims to optimise relational capacity of individuals and teams to support the delivery of compassionate care to older people. A four month implementation programme designed for hospital ward nursing teams caring for older people, but relevant to other teams working with other client groups. (UK) | This evidence-based intervention is designed to develop and sustain the relational work required by managers and team members to support care delivery and has the potential to address widely documented variations in care quality. Describes importance of carer engagement and staff working in partnership with carers. | Little is known about the feasibility of the intervention in practice. Possible issues are identifying carers and how teams of staff communicate with carers and share information about patient care. | Novel implementation programme designed to improve and support the delivery of compassionate care by health and social care teams. Potential to engage carers in immediate improvement in patient care/ hospital environment. |
| Brief Encounters (2014) | Brief Encounters - A resource to promote effective communication between staff and patients/families in hospitals www.brief-encounters.org (REL: High) (GRADE IV) | Provides information about communication issues and explains staff needs and patient needs in relation to clinical relationships and communication in stressful situations, focusing on patients with dementia or cognitive impairment. (UK) | Draws on staff and carer perspectives of communication issues. Considers patient/carers relationships and implications for how staff communicate with patients. | Relies on staff willingness to engage with the resource and apply knowledge in practice. Staff may not recognise older people's mental health needs or the implications for caregiving. | This communication aid can help resolve tensions and support information sharing and relationship building between patients, carers and staff. |
| Carers Trust (2014) | The Triangle of Care is a project based on a guide developed by carers of people accessing mental health services. Six key standards to include, inform and support carers have been extended and adapted by health providers including hospitals. (REL: High) (GRADE III) | Guide designed for inpatient services with focus on mental health but has been revised and extended to other service contexts including carers of older people with dementia when the person they care for is admitted to hospital. (UK) | The UK RCN is using the guide as part of their Dignity in Dementia: Improving Care in Hospital Settings. A new guide: Triangle of Care, Carers Included – Best Practice in Dementia Care has been developed in partnership with carers, people with dementia and professionals to address this particular field of health care. | Staff need training and support to learn about key standards and how they apply to their practice. Management support is needed so that teams can implement the Triangle of Care consistently in practice. | Staff have a better understanding of ways of working with carers. Carers are included, informed and better supported when they are caring for someone with a serious mental health condition or impairment. |

Table 4: Characteristics of included articles

| Subjects | | Study design | |
|--|----|-------------------------------|----|
| Carers/caregivers | 57 | Qualitative | 50 |
| Family carers/relatives | 45 | Quantitative | 27 |
| Expert carers (established family carers) | 1 | Review | 18 |
| | | Mixed-methods | 7 |
| | | Action research | 1 |
| Location of authors | | Condition/context | |
| UK | 39 | Older patients/unspecified | 46 |
| USA | 30 | Dementia/cognitive impairment | 16 |
| Australia | 7 | Frailty/multiple conditions | 7 |
| Canada | 4 | Palliative/end-of-life care | 6 |
| Taiwan | 4 | Hip or knee surgery | 5 |
| Sweden | 4 | Cancer | 4 |
| Norway | 3 | Delirium | 4 |
| Finland | 3 | Stroke | 4 |
| The Netherlands | 2 | Congestive heart failure | 3 |
| Israel | 2 | Elderly care wards | 2 |
| Brazil | 1 | Neurosurgical | 1 |
| Denmark | 1 | Haemodialysis | 1 |
| Korea | 1 | Alzheimer's disease | 1 |
| New Zealand | 1 | Harmful behaviour | 1 |
| Singapore | 1 | Emotional vulnerability | 1 |
| | | Motor neurone disease | 1 |
| Components of carer engagement (themes) | | | |
| <p>Patient caregiving: Avila et al. 2015; Baider & Surbone 2014; Beach et al. 2005; Berthelsen et al. 2014; Boltz et al. 2014; Bridges & Fuller 2014; Carers Trust 2014; Cho & Kim 2006; Clissett et al. 2013; de Vos et al. 2012; Godfrey et al. 2013; Health Quality Ontario 2008; Lane et al. 2003; Laitinen & Isola 1996; Laitinen-Junkkari et al. 2001; Lindhardt et al. 2008; McKee et al. 2003; Marshall et al. 2013; Nahm et al. 2010; Small et al. 2009; Walter-Ginzburg et al. 2001; Wells & Baggs 1997; Woods et al. 2012; Yang & Kirschling 1992; Yuhas et al. 2006</p> | | | |
| <p>Information sharing: Aasen et al. 2012; Alzheimer's Society 2014; Bradway & Hirschman 2008; Cornwell et al. 2012; Ellis et al. 2011; Goodrich & Cornwell 2008; Kodali et al. 2015; Luxford et al. 2015; McKeown et al. 2010; Pennbrant 2013; Robben et al. 2012; Thompson 2011; Toye et al. 2014</p> | | | |
| <p>Shared decision making: Allen 2000; Brief Encounters 2014; Firth-Cozens & Cornwell 2009; Griffith et al. 2004; Jacelon 2006; JRF 2012; Karlsson et al. 2015; Milte et al. 2013; Ng et al. 2013; Walker & Dewar 2001</p> | | | |
| <p>Carer support and education: Abraham & Berry 1992; Douglas-Dunbar & Gardiner 2007; Given & Sherwood 2006; Hendrix et al. 2011; Hendrix et al. 2013a; Hornsey 1994; Leenerts et al. 2007; Li 2005; Li 2004; Li et al. 2003; Lin & Lu 2005; Lockery et al. 1994; McHugh et al. 2012; Morris & Thomas 2001; Nolan et al. 2004; Patterson et al. 2011; Rosenbloom & Fick 2014; Rosenbloom-Brunton et al. 2010; Slatyer et al. 2013</p> | | | |
| <p>Carer feedback: Andrén & Elmståhl 2008; Digby & Bloomer 2014; Ellis 2008; Hudson and Payne 2009; Laitinen 1993; Mackenzie et al. 2007; Matson 1994; Rose et al. 2000; Thomas & Moore 2014; Yeh & Bull 2012</p> | | | |
| <p>Patient care transitions: Baillie et al. 2014; Bauer et al. 2009; Bowman et al. 1998; Bragstad et al. 2014a; Bragstad et al. 2014b; Bull et al. 2000; Coleman et al. 2004; Cotter et al. 1998; Ellins et al. 2012; Giosa et al. 2014; Hanratty et al. 2014; Hendrix et al. 2013b; Holzhausen 2001; Knight et al. 2013; Lenz & Perkins 2000; Lundh & Williams 1997; Mant et al. 2000; Mudge et al. 2013; Naylor et al. 1994; Naylor et al. 1999; Neiterman et al. 2015; Popejoy 2011; Shyu et al. 2008; Shyu 2000; Walker et al. 2007</p> | | | |

Figure 2: Integrated model of carer engagement

